

Talking Mats® help involve people with dementia and their carers in decision-making

Findings
Informing change

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Recent government guidance recommends that people with dementia should be encouraged to express their views and be included in decisions about their care. This project explores how people with dementia and their family carers can use Talking Mats, a low-tech communication tool, to feel more involved in everyday care decisions.

Key points

- Talking Mats can help both people with dementia and their family carers feel more involved in discussions about managing their daily lives.
- People with dementia reported that Talking Mats helped them to clarify their thoughts, express them to their family carers, and reach a decision in these discussions.
- Family carers reported that Talking Mats made them feel 'listened to' by the person with dementia. They also felt that their relative could actually 'see' their point of view when using Talking Mats.
- Talking Mats can contribute to the process of negotiation in day-to-day decision-making. They also offer a method for recording joint views to inform later decisions made with members of the wider support community.
- These findings contribute in a practical way to the current debate on how to meaningfully involve people with dementia and family carers in decisions about care. They are also relevant to the assessment of needs.
- The findings have implications for the organisation, delivery, regulation and improvement of services for people with dementia, as their views and those of their family carers can be recorded to clarify and enhance planning. This is essential if personalised services, and user and carer directed outcomes, are to be achieved.

The research

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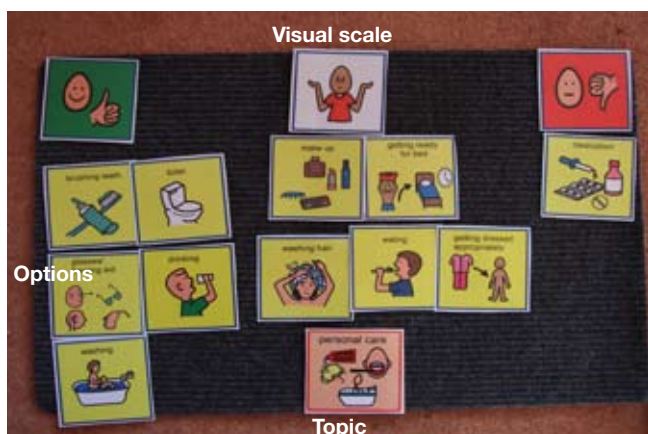
Background

Professionals are now encouraged to involve people with dementia in discussions and decisions about their care. Although autonomy is seen as being important in decision-making, it is acknowledged that people with dementia may have difficulty admitting they are having problems due to memory loss and communication difficulties. Many also cannot manage day-to-day activities without some support from others.

This project explores whether people with early and moderate stage dementia and their family carers can use Talking Mats together to help them feel more involved in decisions about managing their daily lives.

Talking Mats is a low-technology communication framework, developed at the University of Stirling, to help people with communication difficulties express their views. A simple system of picture symbols, placed on a textured mat, allows people to indicate their views about various options within a topic by placing the relevant image below a visual scale (see Figure 1).

Figure 1: Example of a Talking Mat



This example shows a mat completed by a couple discussing how the person with dementia was managing their personal care.

Talking Mats and involvement in decision-making

The main finding from this study was that people with dementia and their family carers both feel more involved in discussions when using Talking Mats, compared to their usual communication methods. They also feel more satisfied with the outcome of these discussions.

People with dementia reported that Talking Mats clarified their thoughts and enabled them to express their views. The framework allowed them to convey their thoughts to their family carers, and helped them to reach a decision about how they were managing different aspects of their lives.

I found it [Talking Mats] a big help, sometimes I get the words muddled and can't get out what I am trying to say.

It is so difficult to tell [my wife] what I think when I can't remember the words, the pictures could help me a lot.

The mat shows that I am able to do much more than I thought.

I didn't realise how much she is doing in the house.

(People with dementia)

A similar pattern was also evident in responses from family carers, who acknowledged the value of Talking Mats in encouraging and maintaining communication.

It [Talking Mats] gives a focus to your conversation, it can be so difficult sometimes to find out what he feels.

I can definitely see a place for it [Talking Mats] when communication really becomes a problem.

(Family carers of people with dementia)

An unexpected finding was that, although the people with dementia and family carers both felt more involved in discussions using Talking Mats, the increased feeling of involvement was significantly higher for the family carers. Family carers repeatedly reported feeling 'listened to' by the person with dementia and felt that their loved one could actually 'see' their point of view.

[With Talking Mats] it really feels like he is listening to my point of view, even for that moment.

It never seems like he is listening to me, with this I can make him sit down and look at symbols and get him to understand what I am trying to say.

(Family carers of people with dementia)

Mats demonstrates an innovative and positive approach to helping carers and people with dementia discuss the management of everyday activities. For both, 'living well with dementia' involves a complex balancing act between negotiating changing needs and preferences in everyday life, and making choices about current and future support.

Talking Mats provides a framework whereby the needs and views of the person with dementia and their family carer can be articulated and shared. By facilitating such conversations, it may be possible to identify strengths and abilities, correct misperceptions about abilities and preferences, reduce anxiety on the part of both the person with dementia and their family carer,

Practical implications

The project findings contribute in a practical way to the current debate on how to meaningfully involve people with dementia in decisions about their care. Talking

Table 2: Relevance of Talking Mats to government recommendations and guidelines

Document	Recommendations / guidelines
Adults with Incapacity (Scotland) Act (2000) Mental Capacity Act (2005)	<ul style="list-style-type: none"> • Recommends involvement of people with dementia in decision-making. • Maintains the rights of individuals to be supported to make their own decisions. • Suggests that alternative methods of communication should be used.
National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006)	<ul style="list-style-type: none"> • States that people with dementia should: <ul style="list-style-type: none"> – be involved and in control of their own living arrangements and support on a day-to-day basis; – have their voice heard in person-centred care planning and reviews; – have their voice heard in the regulation, development and improvement of services and support systems; – be involved in decisions about key life choices and transitions; and – be involved in decisions about care and treatment. • Encourages professionals to involve people with dementia in discussions and decisions about their care. • Recognises the contribution that family carers make and their own need for support.
Commission for Social Care Inspection (2006) National Audit Office (2007)	<ul style="list-style-type: none"> • Defines a care pathway and sets targets to improve quality of care and outcomes.
Putting People First, Department of Health (2007)	<ul style="list-style-type: none"> • Recommends giving more choice and control to people who use services.
Carers Strategy, Department of Health (2008b)	<ul style="list-style-type: none"> • Highlights the need to negotiate the right kind and levels of support that balance the needs and choices of both the person with dementia and their carer.
Living well with dementia: A National Dementia Strategy, Department of Health (2009a)	<ul style="list-style-type: none"> • Focuses on outcomes in relation to three main themes which involve including the views of people with dementia and their carers: <ul style="list-style-type: none"> – raising awareness and understanding; – early diagnosis and support; and – living well with dementia. • Aims for services to be responsive to the personal needs and preferences of each individual and take account of broader family circumstances (Objective 6). • Recognises that family carers are the most important resource for people with dementia and an agreed plan to support their role is essential (Objective 7).
Dementia Strategy Consultation Paper, Scottish Government (2009)	<ul style="list-style-type: none"> • Focuses on rights, dignity and personalisation.
National Dementia Action Plan for Wales consultation (2009a)	<ul style="list-style-type: none"> • Includes initiatives to improve choice and control, and the personalisation of care.
Alzheimer's Society Northern Ireland consultation (2009)	<ul style="list-style-type: none"> • Pledges that research involving the views of people with dementia will inform the work of the group.

and help them express their concerns in a safe, non-confrontational way.

This study demonstrates that Talking Mats could enable people with dementia and their family carers to jointly discuss and make decisions about daily activities – an important discovery for health, care and other staff (such as Housing and Benefit Agency staff) who assess needs and provide care and support. Staff working within these sectors must be able to not only identify the specific needs and preferences of people with dementia, but also take into account the views of family members and work with them. Talking Mats can not only contribute to the process of negotiation in day-to-day decision-making, but also offer a method for recording views to inform later decisions made with members of the wider support community.

Policy relevance

The findings presented here have implications for the organisation, delivery, regulation and improvement of services for people with dementia. Recent guidance, from both the Department of Health and devolved governments, recommends that people with dementia should be involved in decisions about care options and key life transitions.

Government policy also advocates that users and carers should influence how government strategies and targets are implemented. The findings from this study suggest that Talking Mats can support people with dementia and their carers in expressing their views about services, and could therefore be a significant help to those implementing policy and seeking to change practice.

Table 2 highlights some of the recommendations and guidelines described in government documents and relevant to the Talking Mats framework.

Conclusions

This project has shown that people with dementia and family carers can use Talking Mats together to feel more involved in making decisions about managing daily life.

This in turn could lead to increased well-being and positive adjustment to accepting increasing levels of care. Perhaps most importantly, Talking Mats has the potential to help improve the relationship between the person with dementia and family carers, if all involved feel that their views have been acknowledged.

The next step must be to put this knowledge into practice. If, as policy-makers suggest, the focus is now to truly engage people with dementia and their families in decisions about their care, it is clear that Talking Mats offer an innovative means of allowing the views of people with dementia and their family carers to be heard.

About the project

The project ran over a 21-month period from April 2008 to December 2009. It was carried out by Joan Murphy and Tracey Oliver at the Talking Mats Research and Development Centre, University of Stirling.

Eighteen couples (person with dementia and a family carer) were asked to discuss how the person with dementia was managing four aspects of daily living:

- personal care (washing, dressing);
- getting around (walking, using the stairs);
- housework (cooking, making the bed); and
- activities (watching TV, listening to music).

Couples talked about these topics using both Talking Mats and usual communication methods (verbal discussion) to discuss whether they were 'managing', 'needed assistance' or 'not managing' in each area. Afterwards, the couples were asked to complete a short questionnaire to determine how involved they felt in each type of discussion.

Further information

For more information about the project and Talking Mats training please go to www.talkingmats.com

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